

What Should We Expect of Assistive Technology?

Being Sensitive to Family Goals

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Family members often express these and other concerns during assistive technology decision-making processes. This article examines family concerns, goals, and expectations related to students' use of assistive technology. The article serves as a question-and-answer forum that may be helpful for Individualized Education Program (IEP) team members as they address family goals and expectations. Our first question is "What is assistive technology?"

What Is Assistive Technology?

To ensure effective team decision making, IEP team members must help family members understand that assistive technology includes both devices and services.

An *assistive technology device* is defined in the Individuals with Disabilities Education Act (IDEA) of 1997 as "any item, piece of equipment, or product system . . . that is used to

increase, maintain, or improve the functional capabilities of children with disabilities" (20 U.S.C. 1401[25]). Examples of frequently used devices in classroom settings include

- Simple communication boards and wallets.
- Sophisticated electronic communication devices.
- Mobility aids, such as long canes and powered wheelchairs.
- Expanded or adapted keyboards, touch windows, and speech recognition systems.
- Magnification devices and computer screen reading adaptations.

An *assistive technology service* is defined as "any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device" (20 U.S.C. 1401[25]). Examples of assistive technology services provided in the public schools include physical therapy, occupational therapy, and speech therapy.

As IEP team members, we consider assistive technology and reasonable accommodations and modifications planning process as ways to address the individual needs of a child with a disability. Based on individual needs, we determine what assistive technology

"Those professionals on the individualized education program (IEP) team don't understand that my child won't use that device at home!"

"I didn't realize that my child's electronic speech device would take so long to learn to use!"

"You want me to go to how many workshops to understand that device?"

devices and services are required for the child to benefit from special education. As we consider devices and services, we need to remain sensitive to family goals and expectations.

Why Are Family Goals and Expectations Important?

It is mandated by law—and recognized as best practice in the field of special education—that families be actively involved in making decisions about assistive technology that is being considered for their children (Bowser, 1999; King, 1999). Many teams have found, however, that family decisions involved in such processes are often heavily influenced by cultural/linguistic backgrounds (see VanBiervliet & Parette, 1999). For example, African American family members may prefer not to use assistive technology devices that call attention to their children in public settings (Huer, 1999a, 1999b). The time required for training to use assistive technology devices, attendance at workshops, or transporting devices in the community might be issues for a Native American family (Stuart, 1999). Hispanic family members may choose to use assistive technology devices that encourage cooperation versus competition. The culturally and linguistically

IEP teams determine what assistive technology devices and services are required for the child to benefit from special education.

based values reflected in the preceding examples wield strong influence on family perceptions of assistive technology.

To ensure that family voices are heard in this process, and to minimize the possibility of assistive technology abandonment (Phillips & Zhao, 1993), we should carefully consider *family goals and expectations* regarding assistive technology for their children. Such family goals and expectations are often quite different from those of professionals (Parette, VanBiervliet, & Hourcade, 2000).

Table 1 shows issues relevant to family goals and expectations regarding assistive technology, potential outcomes (both positive and negative), and IEP team responses. This information is designed to raise educators' awareness regarding the importance of family goals and expectations that are identified early in the planning process. Once team members have identified specific goals and expectations, they may find suggestions for positive outcomes on the table.

What Questions Should Team Members Ask Family Members?

On examining the various family expectations/goals presented in Table 1, we need to consider four specific questions when working with families.

What Are the Family's Expectation for Child Independence?

Educators and other IEP team members often view assistive technology as a vehicle through which students may achieve greater independence. Although many families of children with disabilities feel that their children should be as independent as possible in their daily life activities (Pengra, 2000); other families prefer that their children remain *dependent* in family and community settings. This preference contradicts what

many special education professionals advocate for children and expect of families. Dependency may be a function of familiarity with others in the family's community, established routines, or a cultural characteristic. For example, many Asian or Hispanic families may perceive the child's disability in religious terms (e.g., a response to past sins of the parent or an "act of God"). Also, there may be a strongly held sense that families should "stick together," live in close proximity to one another, and support one another across the lifespan (see box, "Case Study 1").

Although continued dependence may be a preference for some families, many others will clearly be supportive of nurturing their children's independence.

Questions that team members should ask the family include the following:

- Will you use assistive technology in community settings outside the home?
- What skills or commitment will be required of others in the community for your child to be able to successfully use the assistive technology device?

Case Study 1

Mr. and Mrs. Sanchez have a large immediate and extended family in the community. They have reported to the IEP team that there are four generations of their family living within a few blocks of one another, and that they are a very "close" family.

An IEP team member suggests that Maria, their child with mental retardation, might benefit from physical and occupational therapies to increase her independence with daily life activities. "This would also increase the chances of her living by herself and holding a job outside the community when she is older," asserts the team member.

The parents grew quiet on hearing this recommendation, noting the feeling that Maria will most likely remain at home as she grows older and be taken care of by her family.

We should carefully consider family goals and expectations regarding assistive technology for their children.

- Do you want your child to perform routine daily tasks, or do you or other family members expect to do daily tasks for the child?

To What Extent Does the Family Want the Child Accepted by Others?

Many family members, particularly mothers, are especially concerned that their children be accepted in social settings (Angelo, Jones, & Kokoska, 1995). Generally, assistive technology can assist many children with disabilities to more effectively be included with others and perform a wide range of tasks across environmental settings. If family members, with whom the team may be working, value the importance of inclusion for their children, they may be much more inclined to expect assistive technology that can help facilitate such a goal.

Although professionals may believe that assistive technology can assist children with disabilities find acceptance in school and community settings (e.g., using an augmentative and/or alternative communication device to aid in communication; using a motorized wheelchair for mobility), many families will express concern that devices will draw undue attention to or stigmatize the child (Smith-Lewis, 1992). As noted by Brookes (1998): "Assistive devices become a signal because the sight of a person using assistive technology sends a message that this is not an ordinary person and that one needs to behave differently around this person" (p. 4).

When the family is already coping with the stigma of minority status, this problem may be particularly exacerbated given that the family may perceive a double stigma associated with the provision of assistive technology (i.e., the child is now different both because of race, disability, and the use of assistive technology that draws attention to the

Family feelings about assistive technology are often heavily influenced by cultural/linguistic backgrounds.

Table 1. Family Goals and Expectations Regarding Assistive Technology, Potential Outcomes, and IEP Team Responses

Goal or Expectation	Potential Positive Outcomes	Potential Negative Outcomes	IEP Team Responses
Child will immediately use assistive technology device	<ul style="list-style-type: none"> • Rapid adaptation to device • Enhanced family self-esteem • Increased caregiver time to pursue other activities • Increased family involvement with child • Intense involvement of professionals in training child and family • Development of user-friendly training and support materials 	<ul style="list-style-type: none"> • Failure to use device due to initial and ongoing training needs • Intensive training required • Professionals may have little or no interest in assistive technology • Increased commitments of family time to use assistive technology in natural settings • Changes in family routines to accommodate device usage with child • Increased assistive technology transportation demands • Ongoing availability to ensure device usage • Increased levels of stress • Technology abandonment 	<ul style="list-style-type: none"> • Provide required information regarding training, maintenance, and transportation • Share information re: device and service demands • Determine willingness of families to use assistive technology across settings • Identify training needs of all family members • Provide direct training with user-friendly materials • Use support groups to provide training and information
Change in level of functioning	<ul style="list-style-type: none"> • Rapid improvement of child functioning • Increase in skills in other developmental areas • Family satisfaction with device or service 	<ul style="list-style-type: none"> • Choosing between quality of life and assistive technology implementation • Slow progress • Increased progress followed by plateau • Frustration • Illness episodes resulting in decrease in assistive technology proficiency • Increased stress levels • Technology abandonment 	<ul style="list-style-type: none"> • Help family to celebrate small changes in behavior related to assistive technology usage • Provide information re: anticipated family time commitment to use assistive technology • Assist families in problem-solving re: organization of time for assistive technology implementation • Provide direct training to family • Use support groups to help families deal with device/service-related stressors
Acceptance in community	<ul style="list-style-type: none"> • Greater access to services and activities • Heightened independence • Less dependence of child on family for successful interactions in community • Heightened child and family self-esteem • Willingness of community members to learn to use assistive technology 	<ul style="list-style-type: none"> • Inability of family to predict ways assistive technology will be used in community • Community members may not understand how to interact with child • Undue attention drawn to child and family • Family may refuse to use assistive technology in social settings • Family must transport device across settings • Financial responsibility may discourage assistive technology usage in community • Increased stress levels • Technology abandonment 	<ul style="list-style-type: none"> • Identify contexts for assistive technology usage and demands on effective usage • Clarify family responses to social usage of assistive technology in community settings • Provide training to child, family, and others in natural settings • Anticipating how assistive technology may be potentially used in community • Identify easily transportable devices • Clarify financial responsibilities for assistive technology and develop solutions to optimize use in community

Table 1. Family Goals and Expectations Regarding Assistive Technology, Potential Outcomes, and IEP Team Responses (continued)

Goal or Expectation	Potential Positive Outcomes	Potential Negative Outcomes	IEP Team Responses
Immediate and ongoing access to assistive technology	<ul style="list-style-type: none"> • Funding source may secure device or service promptly once decision is made • Loaner device may be available to child and family during funding and repair intervals 	<ul style="list-style-type: none"> • Funding source may require inordinate period of time, resulting in frustration and anxiety for family • Loaner devices may not be available for child and family use during repair and funding intervals 	<ul style="list-style-type: none"> • Ensure availability of loaner devices or other alternatives • Clearly communicate timelines required for funding and repair intervals
Child will be more like other children	<ul style="list-style-type: none"> • Child may interact more effectively with others in natural settings • Child will demonstrate skills and abilities previously not possible without the use of assistive technology 	<ul style="list-style-type: none"> • Child may be perceived to be different • Reduced child interactions with others • Family and others must assume responsibility for availability of assistive technology for child's participation in activities • Increased levels of stress • Technology abandonment 	<ul style="list-style-type: none"> • Provide information and training to children with whom child will interact regarding nature of device or service and how to use appropriately • Determine responsibility for transportation of devices across settings
Device or service usage will lead to ability to use other devices (e.g., computers)	<ul style="list-style-type: none"> • Use of devices or services may develop prerequisite skills important for use of other devices (e.g., fine motor control, tracking skills, keyboarding) 	<ul style="list-style-type: none"> • Assistive technology may require use of splinter skills unrelated to use of a computer or other devices deemed important to families 	<ul style="list-style-type: none"> • Identify and communicate features of devices and services and the relationship of skills developed to family preferences, priorities, and needs

Note: IEP - individualized education program.

Source: Based on structured interview and family focus group reports reported in Parette, H. P., Brotherson, M. J., Hoge, D., & Hostetler, S. A. (1996, December). *Family-centered augmentative and alternative communication issues: Implications across cultures*. Paper presented to the International Early Childhood Conference on Children with Special Needs, Phoenix, AZ. © 1996 by Howard P. Parette. Reprinted with permission.

child). Families with cultural or linguistic backgrounds valuing *acceptance* and *blending into* a community, may reject the use of devices that draw undue attention. If team members expect use of the device in public settings, assistive technology devices must easily accepted by others (see box, "Case Study 2").

Questions that team members should ask include the following:

- Are there reasons not to use the assistive technology outside the home?
- Will assistive technology make you or your child feel self-conscious or cause undue attention if used in public settings?
- How will people around you and your child feel if assistive technology is used outside the home?

What Are Family Expectations Regarding Immediacy of Benefits?

Interestingly, the promise of assistive technology in meeting the needs of children with disabilities is contingent on understanding its *appropriateness* for a particular child and family. While appropriateness has been addressed by many individuals offering various strategies for assistive technology assessment and prescription (see e.g., Church & Glennen, 1992; Flippo, Inge, & Barcus, 1995; King, 1999; Parette, Brotherson, & Huer, 2000), team members may often fail to obtain input from family members regarding expectations of the immediacy of results of assistive technology. This is problematic from a cultural/linguistic perspective. For example, Asian family members may

want to see immediate results if an electronic speech device is provided for their child, without regard to the amount of training that may be required to effectively use the device (Huer, 1999a, 1999b; see box, "Case Study 3").

A Hispanic family may want the child to immediately be able to use the device at an important family celebration (e.g., the *quincanera*; Huer, Parette, & Saenz, 2001). After an assistive technology evaluation is conducted, it may become apparent that the child can effectively use a device, yet the family is told that the funding process may take weeks or months before the child will receive the device.

Similarly, a family may expect rapid changes in the child's functioning on receipt of the device, without considera-

tion of the training required by the child and family, limitations of the device, and other implementation issues. If family expectations are not considered and the device fails to live up to those expectations, the child or family may opt for abandonment of the device in family and community settings.

Questions that team members may ask during the planning process include the following:

- What do you think the assistive technology device will do for your child?
- How will you and your child use the device?
- What benefits can you expect?
- Do you expect benefits to be immediate?
- What training will be needed?
- How will you pay for the device?
- How often will your child use the device?
- Will your child need assistance?
- Who will provide the assistance?

What Are Family Resource Commitments to the Implementation of Assistive Technology?

Many people have commented on the tremendous responsibilities often rele-

Case Study 2

Mr. and Mrs. Adams take their family of four out to a local restaurant on Friday night. This is the first time that their child, Takisha, has been allowed to take her newly acquired speech communication device out into public. Mr. and Mrs. Adams were concerned about the device, though the IEP team strongly encouraged the family to use the device in "public settings."

The restaurant is relatively quiet, and while the family interacts with one another the audibility of Takisha's communication device is very noticeable in the restaurant setting. Mr. and Mrs. Adams become aware that everyone in the restaurant seems to be watching them as they converse with Takisha, and finally take her device away and place it on the floor for the remainder of the meal.

Case Study 3

During the first IEP team meeting, Mr. and Mrs. Chin were asked what their assistive technology goals were for their son, Bobby. In the conversations that followed, it became apparent that the family wanted immediate communication results for their son, Bobby, who was nonverbal. The family had seen a demonstration provided by a local vendor of a communication device that "talked."

Bobby was shown how to press several keypads on the device; and the parents heard the words, "I love you," come from their son for the first time. Their intent was clear—they wanted a device just like the one they had seen demonstrated, and they expected that Bobby would be using it *immediately* to communicate his basic needs.

The IEP team was sensitive to the family's expressed goal and acknowledged that the ability to communicate using an assistive technology device was an appropriate goal for Bobby. The team members then systematically provided the family with information regarding the sophistication of the communication device desired, the amount of training and maintenance that would be required for Bobby, the family, and school personnel before "immediate and sustained" results would be possible. They also asked questions early in their discussions, such as these:

- "Will you be able to attend training to learn how to use the device?"
- "How will attendance at trainings affect your family's routines?"
- "What family members will assist Bobby in implementing his communication device?"

Such interactions helped the team and family more realistically plan for Bobby's effective assistive technology intervention.

gated to families in learning to use assistive technology devices (Angelo, 1997; Parette, Brotherson, & Huer., 2000). Introduction of many assistive technology devices into family settings may result in increased stress for family members, frustration, and other potentially negative effects. Having to transport an assistive technology device (particularly cumbersome ones) across environmental settings may require personal resources that families are unwilling or unable to commit (see box, "Case Study 4").

It should also be considered that if team members recommend that family members commit personal time to travel and attendance at workshops or structured training activities for the purpose of learning to use devices, resistance to use of the assistive technology device may, at times, be anticipated. For other families, quality of life (e.g., peace and harmony within the family) may be more important than committing time and energy toward assistive technology implementation.

Researchers have proposed checklists that can assist in determining whether unnecessary stressors related to family resources are present during the assistive technology decision-making process (Parette & Petch-Hogan, 2000).

The following are some questions teams should ask families about the possible use of assistive technology devices:

- Are there reasons why you wouldn't want to use such a device at home or in the community?
- How do you think it will affect your child with a disability?
- How do you think it will affect your home environment?
- How do you think it will affect your other children? your spouse? other family members?

Final Thoughts

IEP team members should carefully consider families' goals and expectations regarding assistive technology. Family goals and expectations provide the backdrop against which planning should take place, with a range of input and participation being encouraged from the family to ensure that effective assistive technology decision making

Case Study 4

White Dove has cerebral palsy, and the IEP team has determined that she could use a manual wheelchair to assist her in moving about in the environment. When her parents are asked about their family activities during the week, it was discovered that the family—two parents, four children, and two grandparents—typically compact themselves into the family automobile to visit relatives on the nearby reservation. Given the amount of luggage that must be transported, the family noted that it would not be practical for them to carry a wheelchair in the trunk of the car during these routine visits and that the father would prefer to transport White Dove in his arms.

occurs. Such sensitivity to the family has the potential to ensure that appropriate assistive technology devices are identified, secured, and implemented effectively, in school, home, and community settings.

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